

BREAKING GROUND



FULFILLING THE PROMISE [5]



AN INTERVIEW WITH
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BETH'S MUSIC PLACE [8]



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CONTACT INFORMATION



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E-MAIL: breakingground@vanderbilt.edu.

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Feet, Heart & Wings

BY ASHLEY COULTER

When Gabriel is rolled up the ramp at the new Gabriel's Garden playground in Jackson, he feels like all the other kids. Suddenly, and for the first time, his wheelchair doesn't get in the way of his swinging, sliding and playing with his brother and sister.

That's because a community got together to make sure kids like Gabriel weren't left out. Now, Gabriel's Garden is joining a long list of other recreational sites across Tennessee that want children of all abilities to feel included.

On October 11, 2007, a group of over 500 people came together to celebrate children with and without disabilities being able to do the one thing that all kids love to do—play! As the children's choir sang "Angels Around Us" and bubbles floated toward the sky, children ran, rolled and were carried through the archway onto the new playground. "I wish everyone considering building a barrier-free

playground could have seen the faces of the children as they entered the play area!" said Darlene Walden, Gabriel's mother and coordinator of the project. "For many, this was the first time they were included in play on a playground. People from all over our city have commented that it was one of the most moving scenes they have ever witnessed."

Gabriel's Garden began as the dream of one family, specifically the children of one family. Three siblings wanted to play together and, with that idea, the Walden family approached the City of Jackson's Parks and Recreation Department asking for their support and blessing. A planning committee, consisting of parents, special education teachers, physical therapists and businessmen, was formed. According to Ms. Walden, most of the funding—totaling almost \$500,000—came from corporate sponsors. Several fundraising events helped too, including a gospel concert, barbecue benefit and

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Photo by Darlene Walden

Photos by Darlene Walden

Easter egg hunt. Fund-raising jars were set up at local businesses and the word was spread through every media outlet in the area.

People from every walk of life, bringing a variety of strengths and abilities to the table to get the work done, were the “feet” of the project. The children with disabilities in the community were the “heart”, as they actively campaigned for the new playground. Finally, the generous donors gave the project the “wings” to take off and become a reality.

“We had the support of the City and the County governments,” said Ms. Walden. “This made all the difference in the world.” The land for the playground was donated, and the City ensured that the grounds would be maintained once the playground was completed. School children saved their spare change and one family even donated the money they would have typically spent in a month on snacks!

Once the money was raised, the construction of Gabriel’s Garden began. There are many elements that make this playground unique and barrier-free. The first difference that one would notice when comparing this playground to a standard one is the smooth play surface. This means the transitions from parking lot to sidewalk to play surface are smooth, which makes it easier and more enjoyable for everyone. There are also ramps at Gabriel’s Garden and the holes in the ramps are specifically designed so that walkers and canes will not get stuck on the journey to the top. The ramps are also wide enough for two wheelchairs to travel up and down, or so that a child in a wheelchair and his or her sibling can race each other to the top!

The height of the structure is an important feature. The highest level is over five feet off the play surface, which allows children who use wheelchairs to feel as if they’re flying! There is also a PECS (Picture Enhanced Communication Symbols) panel, so children who are non-verbal can communicate what activity they wish to participate in, whether it’s playing on the swings or going down the slide. “Since Jackson has the West Tennessee School for the Deaf, it was also important for us to include a panel with the finger alphabet,” said Ms. Walden. “Never again should a child be a spectator in what is the greatest component of childhood – play.”

Find the “feet”, “heart” and “wings” of your town and let people know what a wonderful addition barrier-free playgrounds can be to a community. When asked what advice she would give to an individual wishing to build a barrier-free playground in his or her area, Ms. Walden said, “DO IT! Get started NOW! The benefits are far more than just providing a place for children to play together. Gabriel’s Garden brought our community together.”

Not only did this new playground bring the community together, it brought a family together by giving Gabriel, his brother, Russell, and his sister, Kati, the chance to finally play together in one place.

Ashley Coulter is disability resource specialist/activities coordinator at Tennessee Disability Pathfinder and a member of the 07–08 Partners in Policymaking™ Leadership Institute.



Many city parks and school playgrounds have included barrier-free and access-friendly components for children with disabilities. This is a short and by no means exhaustive list of some other parks that were created specifically to welcome children of all abilities. Check with your local parks and recreation department for specific information about playgrounds in your area.

Ashley Nicole Dream Playground, Knoxville

Darrell’s Dream Playground, Kingsport

Lilly’s Garden, Nashville

Little Buddy Park, Clarksville

Ryan’s Place, Collierville

If you would like to let Pathfinder know about a playground in your community, please email the information to tnpathfinder@vanderbilt.edu.

Fulfilling the Promise:

Tennessee Services *and* Supports for Persons *with* Developmental Disabilities *other than* Mental Retardation

Photo by Deana Claiborne



BY DEANA CLAIBORNE

Charlette Zemba says she was born with the wrong disability—at least in Tennessee. “If I had mental retardation, I could be getting the services I need,” says Ms. Zemba, who now lives in a Tennessee nursing home. “This is not right for me, but I have nowhere else to go.” Ms. Zemba

has cerebral palsy and requires personal supports for virtually every activity of daily living. She was sent to live in a nursing home after the death of her mother, who was her primary caregiver. “My father just couldn’t take care of me,” says Ms. Zemba.

Rudy and Tammy are the parents of 14-year-old Morgan, who has autism. According to her parents, “At home, our days consist of endless prompting to help Morgan transition. From waking and getting out of bed, going to the bathroom, eating meals, planning and supervising activities for every minute, then bathing and getting Morgan ready for bed—all of this requires assistance that can range from verbal or visual prompting to hand-over-hand help. As we look to the future, there are many unanswered questions on how we will continue to meet her needs. Two years ago, we were told to apply for the Medicaid Waiver, because Morgan would need to be in line to get services. We called and set up an interview. But we were told that Morgan does not qualify for the Medicaid Waiver because her IQ is above 70. Morgan needs just as much support as people with mental retardation, but because her disability is the ‘wrong’ type, we are not eligible for those services.”

Developmental Disabilities

Title 33 is the Tennessee State law that addresses developmental disabilities and defines them as conditions based on having either a severe chronic disability or mental retardation.

“Severe, chronic disability” in a person over five years of age means a condition that:

- (A) *Is attributable to a mental or physical impairment or combination of mental and physical impairments;*
- (B) *Is manifested before age twenty-two (22);*
- (C) *Is likely to continue indefinitely;*
- (D) *Results in substantial functional limitations in three or more of the following major life activities:*
 - (i) *Self-care;*
 - (ii) *Receptive and expressive language;*
 - (iii) *Learning;*
 - (iv) *Mobility;*

(v) *Self-direction;*

(vi) *Capacity for independent living; and*

(vii) *Economic self-sufficiency; and*

(E) Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is likely to continue indefinitely and to need to be individually planned and coordinated.

“Severe, chronic disability” in a person up to five years of age means a condition of substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disability as defined for persons over five years of age if services and supports are not provided.

Title 33 made persons with developmental disabilities other than mental retardation, such as autism, cerebral palsy, spina bifida and many other types of disabilities acquired in the developmental stages of life, eligible for services beginning on March 1, 2002. However, no dollars were allocated for these services and no services have been implemented.

The Developmental Disabilities Task Force

In 2006, the General Assembly passed Public Chapter 604, a bill authorizing the Division of Mental Retardation Services (DMRS) to establish a Developmental Disabilities Task Force to study the needs of Tennesseans who have a developmental disability other than mental retardation, to assess the capacity of the service system in Tennessee to serve individuals with developmental disabilities other than mental retardation and to develop a plan for cost-effective home and community-based services for these individuals. The Task Force, including relevant State agencies, persons with developmental disabilities, family members and professionals in the non-profit sector, was formed as a result of this legislation.

Needs of Persons with Developmental Disabilities other than Mental Retardation

People with developmental disabilities are either born with a disability or they acquire the disability early in life. This means that every aspect of life development can be affected, including social and educational advancement, the ability to develop life management skills and the ability to gain employment skills sufficient to earn a living that will cover the expanded costs associated with the lifelong need for specialized care.

With the right supports, many persons with developmental disabilities can become completely self-sufficient as adults. Without the right supports, many persons with developmental disabilities are destined to lives of poverty and institutionalization. An appropriate system of services and supports provides intervention throughout the developmental years and during the stages of life in which independent

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A CONVERSATION *with* MARY V. JORDAN, President of The Arc of the United States



Breaking Ground recently had the opportunity to ask Tennessean, Mary Jordan, about her role as president of The Arc of the United States. Ms. Jordan is the first African American to serve as president of The Arc since it was founded in 1950. As a longtime advocate and volunteer in her local chapter, The Arc of Washington County, Ms. Jordan has strong ties to the organization having previously served as The Arc's vice president. She is also a member

of the State of Tennessee Developmental Disabilities Planning and Policy Council and sits on many committees and task forces at East Tennessee State University.

BG: If you don't mind us asking, what is your personal connection to the disability community?

MJ: My personal connection to The Arc stems from an experience I had when I was 14 years old. That Summer, my family moved to El Paso, Texas, and I took on a summer job as a care taker and companion for a thirty-eight-year-old woman with an intellectual disability. It struck me at the time as kind of amazing that I was charged with caring for someone who was more than twice my age. And yet, despite her disabilities, the woman for whom I cared was an extremely gifted pianist.

The lesson I learned that Summer has stayed with me throughout my life and that is that each individual has his or her unique gifts and abilities and should have the opportunity to share them. That experience set me on the course that has led me to where I am today. It has been my life's work to fight for human and civil rights for all people.

BG: Can you tell us some of the most important issues that have surfaced for The Arc US during your term as president—and those on the near horizon?

MJ: While we have made many strides, there are a host of important issues facing those with intellectual and developmental disabilities and their families. As president of The Arc, my goal is for the organization to take strong action and bring our disability agenda to the forefront. I want our collective voice to be heard

and for The Arc to step forward with a unified call to action. We can accomplish this by strengthening our public policy agenda to end waiting lists, fund family support, address wages and benefits for direct support workers, and protect and increase entitlement programs.

"As president of The Arc, **MY GOAL** is for the organization to take strong action and bring our disability agenda to the forefront."

BG: Do you have some personal "soapbox" issues that you'd like to see addressed before you complete your term?

MJ: One of the more pressing issues that I have made a priority is waiting lists for individuals not getting the services they need or want. The Arc has been very involved in coordinated efforts to address the crisis of state waiting lists for people with intellectual and developmental disabilities. In our home state of Tennessee, more than 5,000 individuals are on the waiting list, of which 1,000 are in crisis with little hope of being served within the next several years.

BG: We're so proud of you being from our State! In what ways did your roles as special assistant to the president for Equity and Diversity at East Tennessee State University (ETSU) and member of The Arc of Washington County help prepare you for this position?

MJ: My work as special assistant to the president for Equity and Diversity at East Tennessee has helped to prepare me to take the helm of The Arc because both organizations share common values. At ETSU, we have core values which I carry with me on my business cards. These are: People come first, are treated with dignity and respect, and are encouraged to achieve their full potential; Relationships are built on honesty, integrity, and trust; Diversity of people and thought is respected; Excellence is achieved through teamwork, leadership, creativity and a strong work ethic; Efficiency is achieved through wise use of human and financial resources; and Commitment to intellectual achievement is embraced. The Core Values of The Arc are: People First, Democracy, Visionary Leadership, Community Participation, Diversity and Integrity and Excellence.



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living skills are maturing. This ensures that people are able to develop to their fullest capacity and may reduce the need for more extensive government supports later in life. Because of the severity of their disabilities, some individuals will need intensive lifelong supports.

Statewide Needs Assessment

The Developmental Disabilities Task Force conducted a statewide Needs Assessment to learn about the most critical needs of persons with developmental disabilities other than mental retardation in Tennessee. The primary targeted population for the survey included persons with developmental disabilities other than mental retardation who are in the Family Support program or on the waiting list for Family Support. Agencies serving persons with developmental disabilities also participated in the survey.

Of the 1,127 persons who responded to the question about needing additional services, 858 (76.1%) indicated they need additional services. The top ten needs as identified by the 1,159 survey respondents were:

1. **Information and Referral** – someone to provide information about available services and how to apply for them;
2. **Therapy** – physical, occupational or speech therapy;
3. **Respite** – services provided on a short-term basis to offer relief to unpaid family caregivers;
4. **Assistive Technology (or Repair/Maintenance)** – equipment or supplies needed to improve or maintain functional capabilities of persons with disabilities; may also include maintenance or repair of equipment or supplies;
5. **Transportation** – public or private transportation to access services or necessary community resources;
6. **Home Modifications** – changes to the home to make it more accessible;
7. **Employment Services** – services to help persons with developmental disabilities get or maintain a job;
8. **Personal Assistance** – someone to help with everyday activities in the home or in the community; may include assistance with bathing, dressing, taking care of personal hygiene, and other activities of daily living; may also include housekeeping chores and meal preparation;
9. **Service Coordination** – someone to help manage a person's services; and
10. **Education** – postsecondary education.

Major recommendations of the Task Force

After a year of research, discussion and planning, the Task Force produced its recommendations.

1. The State of Tennessee should provide an array of home and community based services to persons with developmental disabilities, consisting of the development of a Medicaid Waiver program and a Personal Support program and the expansion of the Family Support program.

2. TennCare eligibility criteria for Medicaid Waiver home and community based services should include persons who have developmental disabilities.
3. Applicants for services who do not have mental retardation should not be required to undergo intelligence testing in order for eligibility to be determined.
4. Responsibility for administering services for persons with developmental disabilities should be assigned to the Division of Mental Retardation Services in the Department of Finance & Administration.
5. Information and referral and access to the system should be easy, flexible, competent, consistent and timely.
6. Persons with developmental disabilities should be provided the opportunity and support to self-direct their services.
7. An adequate provider network for developmental disabilities services should be developed.
8. Strategies to expand the supply of skilled direct support professionals should be developed and implemented.
9. The Division of Mental Retardation Services' quality management system should be reviewed and expanded as needed to ensure it is responsive to services developed for persons with developmental disabilities.
10. The Division of Mental Retardation Services should establish an ongoing planning process to guide the development and evaluation of home and community based services for people with developmental disabilities.

Recommended Programs

In order to provide a comprehensive array of cost-effective home and community based options for people with developmental disabilities, the Task Force recommends:

- the development of a Personal Support program based on the PASS demonstration project;
- the expansion of the Family Support program; and
- the development of a Medicaid Waiver program.

The Personal Support program would serve primarily people with developmental disabilities who are able to work but whose level of income makes them ineligible for Medicaid services. Providing a limited array of services to these persons will keep them as taxpaying residents living in homes and communities across Tennessee rather than having to give up their jobs and move to a nursing home. A model project (Personal Assistance Services and Supports or PASS) provides personal assistance and other needed services to persons with disabilities other than mental retardation for an average of \$10,400 per person.

Family Support is a cost-effective state-funded program that provides minimal but critical support to persons with any type of disability and their families. It is a very flexible, family-friendly program. Family Support fills gaps in services that no other program fills. In FY 2006, Family Support provided services to 4,307 persons, of whom 2,027 (47%) had a developmental disability other than mental retardation. Many of those

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Beth's Music Place

BY JOYCE SIEVERS

At the 2006 Tennessee Disability MegaConference, attendees were attracted by the cadence of drums heard in the hallways. The doorway, the room and the hall at the presentation of The Rhythmic Arts Program (TRAP) were jammed! Drawn by the rhythmic beat, I made it a point to go to the next TRAP session presented by Eddie Tuduri, who has been a drummer with the Beach Boys and many other musical artists.

As a result of a surfing accident and subsequent recovery, Mr. Tuduri created TRAP, with its emphasis on drumming and percussion, as a vehicle for learning and joy. I was blown away by its impact on the individuals who participated and returned to my agency, Pacesetters, with the desire to begin the program for our adults with intellectual disabilities. However, I had difficulty connecting with the contact for TRAP in Tennessee.

A year passed. Then, at the 2007 MegaConference, Gail Dial—another staff person at Pacesetters—heard the TRAP presentation. She too was deeply moved by the program's effect on individuals. Ms. Dial was able to make contact with Bob Stagner in Chattanooga, who is now the TRAP facilitator in Tennessee.

At the same time, I was looking for a project to fund with my daughter's Memorial Fund at Pacesetters. My daughter, Beth, was labeled with the diagnosis of mental retardation and passed away from cancer in 2002. Beth proved with her life that she listened to her own drummer and she created a life with her own personal rhythm. In her own time, she preceded me on the Council on Developmental Disabilities and was State President of People First. I thought Beth would be delighted to have others listen to their own drummer and rhythm through the TRAP program. Thus, her funds have purchased the drums and percussion instruments for Pacesetters' five Centers that support adults with developmental disabilities in the Upper Cumberland region.

On September 26, 2007, The Rhythmic Arts Program was launched at Pacesetters. Over four sessions, Bob Stagner demonstrated how the integration of drums and percussion instruments create learning tools to address life skills and enhance the body, mind and spirit. Now Pacesetters' five Centers each have their own music room designated with a plaque, "Beth's Music Place", honoring Beth's independent and creative spirit. More than 230 individuals are now exploring and growing in musical and imaginative ways. The beat and the rhythm of Beth's life goes on, thanks to Eddie Tuduri and The Rhythmic Arts Program!

For further information visit www.traponline.com

Joyce Sievers, a graduate of the first Partners in Policymaking class (93–94), recently retired as family support coordinator with Pacesetters, Inc. in Algood and is chair of the Council on Developmental Disabilities.



Photos by Kim Pound



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persons would not be eligible for a Medicaid Waiver. Family Support had an average cost during FY 2006 of \$1,783 per person. No other program can serve as many people for this amount of funding.

After much discussion about funding needs, the Task Force ultimately determined that a modest funding request for these two programs, with incremental increases over the phase-in period, has the best potential for approval by the administration and by the legislature.

Medicaid Waiver Programs

Medicaid Waivers are now the generally accepted means for states to provide home and community based supports and services for persons with significant disabilities who qualify for Medicaid. Once a state Medicaid Waiver program is approved, the federal government pays a percentage of the cost of the program. This is called the Federal Medical Assistance Percentage (FMAP). Tennessee's FMAP rate usually runs around 64%. This means that for every dollar Tennessee invests in Medicaid Waiver programs, the federal government commits almost two dollars.

In order to receive Medicaid Waiver services, individuals must meet eligibility standards. While over 7,600 persons with mental retardation are currently receiving home and community based services in Tennessee, and other individuals are in Intermediate Care Facilities placements, there are still approximately 6,000 people on the waiting list for Mental Retardation services in Tennessee.

Because of the long waiting list for current DMRS programs, the Task Force recommended development of a discrete Medicaid Waiver for persons with developmental disabilities other than mental retardation.

Other Tennessee Services

Apart from DMRS, the only other Waiver services offered in Tennessee are provided through the Commission on Aging and Disability (TCAD). This organization provides some state funded and some Waiver funded services. The Waiver provides a community based alternative to institutional nursing facility care for individuals over the age of 21 who are eligible for nursing home care and meet the program and income eligibility requirements. Typical services include minor home modifications, case management, personal emergency response ("Help" buttons), home delivered meals, respite care, home based personal care assistance and adult day care.

It is important to recognize that the programs offered by TCAD were designed primarily with an adult population in mind. Therefore, no programs are available for children and young people. For the most part, the programs assume that the people served are not striving to meet specific independence goals, such as higher education, employment, home ownership, marrying and creating families of their own. There are limited options for transition services (i.e., from high school to higher education), for independent living skills development or for supports to advance in the workforce.

TennCare and Private Insurance

While some individuals are covered under private insurance plans, many people with developmental disabilities of all types eventually

end up on TennCare. This is because they are turned down for private insurance due to pre-existing conditions. TennCare and private insurance provide essential medical care. However, the services provided by TennCare and under most private insurance must be determined to meet the "medical necessity" standard. This is a high standard and it generally means that there must be a strictly defined medical need. Personal assistance for eating, dressing and personal hygiene may be provided as medically necessary as hands-on care that people cannot perform for themselves or there is not a caregiver who can provide this care.

Dedicated Service Providers

Tennessee has a large number of service provider agencies under contract with the DMRS. Typically, the agencies that provide housing services and supports do not enroll persons with developmental disabilities other than mental retardation because most families cannot sustain the annual cost of care over the period of an individual's lifetime, which could range from \$50,000 to well over \$100,000 per year.

Because there are no dedicated funding streams for persons with developmental disabilities other than mental retardation, there are relatively few agencies that dedicate direct services to this population. From a more positive perspective, the services provided to persons with mental retardation are the same services needed by persons with other types of developmental disabilities. Therefore, if government funding streams could be identified, the existing provider agencies would likely accept persons with developmental disabilities other than mental retardation into their programs as capacity is developed.

Becoming Involved in the "Fulfill the Promise" Initiative

The first, and most important goal is to educate policymakers and legislators. Most legislators are not aware of the significant problems families of persons with developmental disabilities are facing because we have not taken advantage of our opportunities to talk to them about these issues.

Each citizen in Tennessee is represented by elected officials who have the responsibility to listen to the needs of their constituents and to address those needs in the most resourceful manner possible. The single most effective way to convey your message is to make a personal appointment with your legislator and tell your story, simply and directly. This is the goal of the "Fulfill the Promise" initiative, to connect citizens with the policymakers and legislators who have the power to implement positive change. Persons interested in becoming directly involved in the "Fulfill the Promise" initiative can send in their contact information by going to www.FulfillthePromise.org or they can contact one of the following organizations.

Tennessee Council on Developmental Disabilities: 615-532-6615

The Arc of Tennessee: 615-248-5878

Disability Law & Advocacy Center: 615-298-1080

United Cerebral Palsy of Middle Tennessee: 615-242-4091

Deana Claiborne is the executive director of United Cerebral Palsy of Middle Tennessee and a member of the Developmental Disabilities Task Force.

SIBSATURDAYS

BY ROXANNE CARREON

In the United States, there are over six million people who have health, developmental and mental health concerns, most of whom have typically developing brothers and sisters. Additionally, siblings usually have the longest lasting relationship with the person who has a health, developmental or mental health issue. Unfortunately, while there are many programs for parents, programs for siblings are few and far between.

Children don't naturally seek out peer support, so providing them with an opportunity to meet and form relationships with children who "get it" is critical. The Vanderbilt Kennedy Center (VKC) provides a program that does just that. SibSaturdays, the VKC version of Sibshops, provides children, ages 5–13, with an opportunity to meet and share with children whose families are similar to their own.

Not for the faint-hearted, SibSaturdays are packed with fun, high-energy games interspersed with what we call "talking times." While the games help the children get to know each other, it's the talking times that are the crux of the program. In a game-like format, the talking times allow children to discuss their concerns and feelings associated with having a brother or sister with a disability, health or mental health issue. The children aren't required to share their feelings; just being among others who understand is often enough.

Although the group is facilitated by an adult sibling, it's the young children themselves who sometimes make the best teachers for learning positive coping skills. As my son, Cooper, says, "Mom, you're a mom. You don't get it like I do." There is wisdom in those words. As a parent, I know that some of the best support I receive is from other parents. It seems only natural that kids would respond best to those who have similar experiences.



Photo by Melanie Bridges



Photo by Roxanne Carreon

SibSaturdays have few rules, but at the top of the list is the one that the children appreciate the most: no parents are allowed! SibSaturdays is a time just for siblings. For four hours, the world revolves around them; no physical therapy, occupational therapy or speech sessions to attend and no waiting in yet another doctor's office. This time is theirs to play, act silly and just be kids. Judging by how quickly the Vanderbilt Kennedy Center program has grown, it's a much needed service and one that works!

A 2005 survey conducted by Amanda Johnson and Susan Sandall at the University of Washington demonstrated that the Sibshop program

Tennessee Sibling Support Groups

SibSaturdays

Roxanne Carreon
University Center for Excellence
in Developmental Disabilities
230 Appleton Place
Nashville, TN 37203
615-936-5118
rxanne.carreon@vanderbilt.edu

Suzanne Thurman

Williamson County Schools
1320 West Main Street
Franklin, TN 37064
615-472-4130
susiet1@wcs.edu

Tina Prochaska

Sibshops at the Tennessee
School for the Deaf
Tennessee School for the Deaf
2725 Island Home Blvd.
Knoxville, TN 37920
865-579-2429
tinap@tsd.k12.tn.us

Terry Hancock

Box 328 GPC
Vanderbilt University
Nashville, TN 37203
615-322-8160
terry.hancock@vanderbilt.edu

Susan O'Connor

Tennessee's Early Intervention System
(TEIS)
TTU Box 5012
Cookeville, TN 38505
931-372-6242
soconnor@tnitech.edu

Laurel Ryan

UT Boling Center for Developmental
Disabilities
711 Jefferson Avenue
Memphis, TN 38105
901-448-3737
lryan2@utmem.edu
www.utmem.edu/bcdd

provides positive outcomes for children. According to the study:

- over 90% of the respondents said Sibshops had a positive effect on the feelings they had for their siblings;
- Sibshops taught coping strategies to over two-thirds of respondents;
- 94% said they would recommend Sibshops to others; and
- 75% said that Sibshops had an impact on their adult lives.

Furthermore, the survey showed that many aspects of the Sibshop program appeared to serve as protective factors for siblings of individuals with disabilities, a population who is frequently considered "at-risk" and "that these positive results last into adulthood." The authors concluded that "the positive effects of the Sibshop program are not only apparent, but enduring. [Johnson, A. B., & Sandall, S. (2005). *Sibshops: A Follow-Up of Participants of a Sibling Support Program*. University of Washington, Seattle.]

The Vanderbilt Kennedy Center is pleased to announce that it will be partnering with the Down Syndrome Association of Middle Tennessee and the Autism Society of Middle Tennessee to create

additional SibSaturdays programs in the Nashville area. To learn more about the SibSaturdays program or to start one of your own, contact Roxanne Carreon at 615-936-5118 or by e-mail at roxanne.carreon@vanderbilt.edu.

See page 10 for a list of Sibshops in Tennessee. If you know of other sibling support groups, please notify Roxanne Carreon.

The Vanderbilt Kennedy Center leads the National Sibling Research Consortium. For a summary of findings of a national survey conducted by the Vanderbilt Kennedy Center with support of The Arc of the United States, email kc@vanderbilt.edu or call 615-322-8240. VKC researchers will soon be reporting findings of a survey of Tennessee siblings, funded by the Tennessee Council on Developmental Disabilities. Tips and resources fact sheets for siblings will soon be available.

Roxanne Carreon is coordinator of the Vanderbilt Kennedy Family Outreach Center and is a parent of two boys, one of whom has Down syndrome. She coordinates the SibSaturdays program in addition to working with families who have children with special needs.

Dorothy Sweatt

A Profile in Her Own Words

INTERVIEWED BY NANCY HARDIN

Do you have a visual disability or know someone who does? Do you know someone who needs the courage to face the difficulties of life while living with a disability? Even if you cannot answer "yes" to any of these questions, you will enjoy and be inspired by the story of Miss Dorothy Sweatt.

Miss Dorothy lives in the southwest Tennessee town of Selmer and I was privileged to visit her in her home for this interview. We had already spoken to each other by phone before our meeting, so I knew that I was going to meet a remarkable person. Miss Dorothy told me that she had been up since 4:00 am getting ready for our visit. She ushered me around her lovely home, showing me family photos, mementos and her diplomas and certificates, which were clearly among her most prized possessions.

When I asked Miss Dorothy about her diplomas, this is the story she told me. "I was born in West Shiloh and later moved to Corinth, Mississippi, where my father had a country store. I had two brothers and a sister and we were a loving family. My brothers and sister went to school, and my greatest wish was that I might go too. It was hard for me to understand why I couldn't go and I often played with books, holding them in front of me and saying words while I pretended I could read. I have always been blind, but I can see a little light and shape of objects with one eye.

"My parents knew there was a school for me in Knoxville, but it was very far away. My father did not want to send his little girl to a school if it meant she would need to live there and that the family wouldn't see her often. The older I became, the more I wanted to go to school. I would beg and insist that I was not afraid and that I knew I could learn if he would just let me go.

"When I was eighteen years old, my father died. I began right away to beg again to go to school in Knoxville and, after much thought, my mother agreed that I might go to the Tennessee School for the Deaf and Blind. I was so excited about finally being able to go and made the long trip all by myself. I was nineteen years old.

"When I got to school everyone there was kind. I started in the kindergarten class with the little children, but the teacher decided right away that I was too big for the little chairs. My knees were higher than the top of the table and she had bigger furniture brought in for me. I soon finished all the work for the kindergarten and spent the rest of the year in the first grade. The teacher gave me the second grade books to study over the Summer so I would be ready when Fall came.

"When I came back, I went to the second grade classroom but very soon the teacher and the principal told me that my studies over the Summer had made me ready for the third grade! I was so excited. I was in school, and was doing good work. Every year was better except for one time when I had to be absent from school because of appendicitis. I kept on going until I finished my high school education and received my diploma after being in school for nine years and three months.

"That year, The Federation for the Blind sent me to Minneapolis, Minnesota, to learn to be a PBX operator. In those days, PBX

CONTINUED ON PAGE 13→

• **RESPONSE TO INTERVENTION:** • *An* **ALTERNATIVE METHOD** *for* Identifying • Children *with* **LEARNING DISABILITIES**

BY COURTNEY EVANS TAYLOR

Until 2004, with the passage of the Individuals with Disabilities Education Improvement Act (IDEIA), educators identified learning disabilities in children solely through the use of the IQ-Achievement Discrepancy model. This model compares a child's IQ with his or her achievement test scores. If the discrepancy between the two scores reveals a wide enough gap, the child is identified as having a learning disability and is eligible to receive special education services. With IDEIA, policymakers introduced Response-to-Intervention (RTI) as an alternative or supplemental method for identifying learning disabilities in school-age children.

For many educators, RTI is a welcome alternative. Its implementation promises to identify children with learning needs much earlier and encourages a move away from the "wait to fail approach" that is associated with the IQ-Achievement Discrepancy Model. Its multi-tiered system has the potential to better distinguish children who have learning disabilities versus children who have received poor quality of instruction. Assessment data collected throughout RTI implementation provides information to the educator that may allow for improvement in individualized instruction.

In October 2007, special educators and psychologists in Metropolitan Nashville Public Schools (MNPS) participated in a training forum on RTI to gain a better understanding of how the method works and how to implement it in their own districts. The forum was sponsored by MNPS, the Tennessee Department of Education, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC UCEDD), the National Research Center on Learning Disabilities (NRCLD) and the Peabody IRIS Center. Speakers included VKC UCEDD and NRCLD investigators, Doug Fuchs, Lynn Fuchs and Donald Compton; Naomi Tyler, Peabody IRIS Center; and Kathy Strunk and Donna Parker, Tennessee Department of Education.

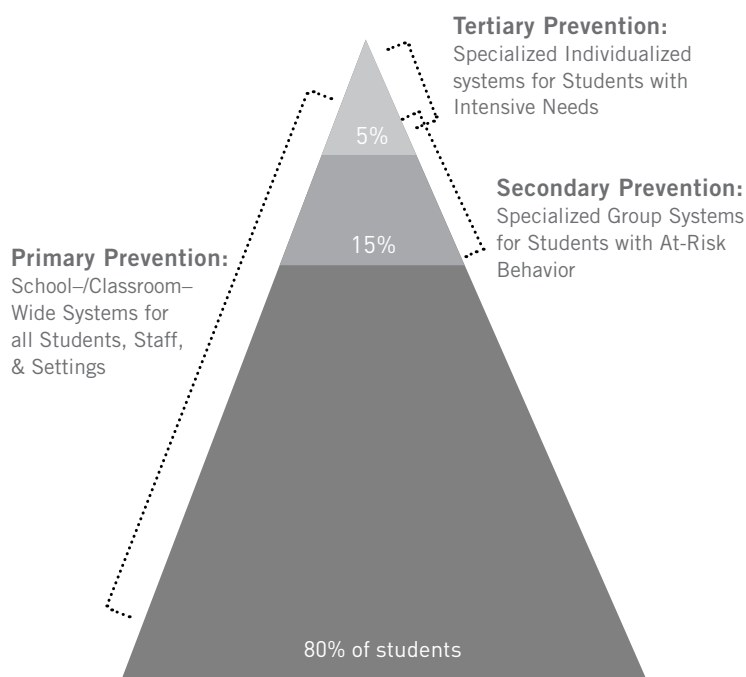
"RTI is not a simple recipe," Doug Fuchs told the educators. "It is difficult to get your hands around, partly because there are numerous ways to set up the program. Though it is possible for many tiers to be set into place, we believe a 3-tier procedure best serves both early intervention and disability identification objectives of RTI."

Lynn Fuchs illustrated what a 3-tier RTI procedure looks like. Tier 1 may be thought of as "primary prevention." In this tier, all children receive universal instruction, are tested once in the Fall, and those who score below the 25th percentile are flagged as "at-risk" and receive tier 2

intervention. Tier 2, or "secondary prevention," begins with what Dr. Fuchs describes as "standard research-validated tutoring protocols" for the at-risk students. Progress is monitored to assess whether students have been responsive or unresponsive to Tier 2 intervention. Responsive students return to Tier 1 and unresponsive students move to Tier 3, "tertiary prevention," [a third level of prevention] to receive a team evaluation and special education services.

"Many students are 10, 11, even 12 years old before they are ever diagnosed with a learning disability," said Doug Fuchs. "They should be diagnosed much earlier and, with RTI, early identification is more of a possibility. Also, with RTI implementation, the number of students who receive special education services should drop. Some students need the services and some just need a little extra instruction to catch up. In most RTI models, it is assumed that 80% of students will be served with Tier 1 instruction, 15% in Tier 2, and five percent are expected to be unresponsive to Tier 2 and therefore identified as having a learning disability."

RTI Research



CONTINUUM OF SCHOOL-WIDE SUPPORT

Doug and Lynn Fuchs collaborated with Donald Compton in implementing experimental RTI studies in the areas of reading and math within MPNS. Their studies had three purposes. "Through the experimental studies, we examined the efficacy of first grade preventative tutoring," said Lynn Fuchs. "We were able to assess learning disability prevalence and severity, with and without Tier 2 tutoring, as a function of identification method. Finally, we wanted to explore pretreatment cognitive abilities associated with

development. We randomly assigned first grade children to various study conditions—assigning some to tier 2 tutoring and others to continue in their classroom program without changes—and did longitudinal follow-up to assess development of long-term difficulty.”

Results following RTI implementation in the area of math revealed that improvement was astonishingly higher in the group that received Tier 2 tutoring versus the group that did not.

“Tier 2 tutoring decreased math disability prevalence at the end of first grade across identification options,” said Lynn Fuchs. “By the end of second grade, math disability prevalence was still twice as high in the untutored group. For this identification procedure, prevalence fell from 9.75% without prevention to 5.14% with prevention. With 53.3 million school-age children, this translates into approximately 2.5 million fewer children identified as having a math disability.”

Similar findings were present in the RTI and reading experimental studies. Donald Compton reported that the tutored group surpassed the performance of the control group and maintained the effects through the end of second grade, significantly decreasing the number of students identified as having a reading disability. Dr. Compton praised RTI, calling it “an inoculation for poor instruction or for initial characteristics of learning disabilities.”

IRIS Center RTI Modules

The Peabody IRIS Center’s RTI module series was presented by Naomi Tyler. The IRIS Center’s mission is to take research from the field and translate it into practical information and tools that educators can use. The RTI modules include topics such as: An Introduction to Monitoring Academic Achievement in the Classroom, Evaluating Reading Progress, Assessment and Reading Instruction, plus an overview that introduces the basic concepts of RTI, including detailed descriptions of its tiers. The modules include sample lesson plans, videos and quotes from the experts. To view the RTI modules visit, iris.peabody.vanderbilt.edu.

RTI is a Choice

“RTI is meant to provide appropriate instruction to students at risk for school failure as soon as possible,” said Doug Fuchs. “This is why many school administrators have restructured general education instruction in their districts into tiers of increasingly intensive instruction. If a student isn’t responding appropriately to mainstream instruction (Tier 1), the student moves to Tier 2 instruction, which may be delivered in small homogeneous groups for a longer duration each day. If the student is still unresponsive to Tier 2 instruction, she may move to instruction even more intensive at Tier 3. Eventually, a chronically unresponsive student will be considered for special education. This has led some advocates to worry that RTI may inadvertently delay disability identification. Most practitioners, however, seem to be interpreting IDEA 2004 to say that if a parent feels strongly that a child has a learning disability, then that parent has the right at any time to by-pass RTI’s tier system and request a comprehensive evaluation for his or her child. So, in a sense, parents seem to have the right to “short-circuit” the process if they wish to do so.”

Tennessee Policies

Kathy Strunk and Donna Parker reiterated the Tennessee Department of Education’s support for RTI implementation in schools. Ms. Strunk mentioned that a school must gain State approval before beginning to use RTI practices to identify learning disabilities in students. This is to be sure the program follows certain standards of excellence. “The IRIS Center modules are perfect for teaching best practices to school systems,” Ms. Strunk commented. “They are informative and cover all the bases.”

Ms. Strunk suggested that cautious schools might take small steps, starting with progress monitoring or even developing a pilot program in a single school to “test the waters.” She made clear that barriers to implementation do exist, mainly in the form of time and money, and that planning is the key.

Courtney Evans Taylor is associate director of Communications and Dissemination at the Vanderbilt Kennedy Center.

Dorothy Sweatt ... CONTINUED FROM PAGE 11 →

operators were the ones who knew how to direct calls to different lines before the days of direct dialing. When I returned home, I had a real job waiting for me as the PBX operator for the Western State Mental Hospital in Bolivar, Tennessee. Since this was very near my home, it was perfect. I had my own quarters on the hospital grounds and worked there for almost 35 years. It was a wonderful job and I enjoyed it very much until I retired in 1988.

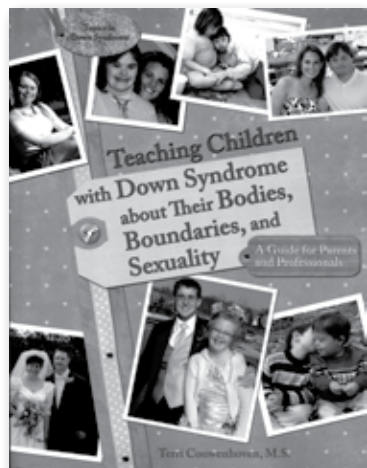
“After I bought my own home, I hoped to have some of my family live here with me, but sometimes life takes different turns and I live here by myself and my sister lives across the street.”

As Miss Dorothy told me about her daily schedule, I could tell that she spent her time well in interesting activities. She said that she was a person who welcomed all the modern changes in the

kitchen—a coffee maker, toaster oven, microwave, etc. These things make it easier to cook in the kitchen. She does her housework, eats breakfast and then she watches “The Price is Right”, “Jeopardy” and the news. She also spends a lot of time reading her Bible tapes. Miss Dorothy says she has read the Bible 30 times! For fun, she also plays solitaire and dominoes. The dominoes were a special gift and each one bears her name on the back.

The one thing I cannot show you on this printed page is Miss Dorothy’s wonderful sense of humor. She enjoys making jokes and is such a delight to talk to. She is not very tall, but she is truly an amazing lady.

Nancy Hardin is a member of the Council on Developmental Disabilities and represents the Northwest Development District.



TEACHING CHILDREN WITH DOWN SYNDROME ABOUT THEIR BODIES, BOUNDARIES, AND SEXUALITY A GUIDE FOR PARENTS AND PROFESSIONALS BY TERI COUWENHOVEN, MS.

PUBLISHED BY WOODBINE HOUSE

BOOK REVIEW BY SHEILA MOORE

The author, Teri Couwenhoven, is first and foremost a parent of two daughters; her oldest has Down syndrome. She is also a certified sexuality educator who specializes in working with people with intellectual disabilities and their families, and Clinic Coordinator for the Down Syndrome Clinic of Wisconsin.

As parents of children with Down syndrome, we are somewhat lost when it comes to addressing the issues of sexuality with our sons and daughters. We often speak with other families and find they too didn't quite know what to do. We start late in addressing the body and its functions and, before we're ready, we are faced with questions, concerns and fears.

The author has drawn from her own experience and background and created an easy guide for parents and professionals to follow in discussing the sexual development of their children. And not just children with Down syndrome. I found the book very helpful in addressing issues with my other child.

The book begins with teaching your child about his or her body, the correct terms to use, caring for the body and issues about privacy, touch and affection. The book continues with friendships and dating, safety and prevention of abuse. The author tackles the tough questions that we're always afraid to ask or discuss.

There are very explicit pictures and aids to assist with teaching and discussing the body parts and their functions. Be ready to answer many questions, if your child views the pictures and is not familiar with the make-up of the male and female anatomies. The book also offers suggestions on how to approach the subjects very early, before major changes or issues occur. Lastly, the book will force you to consider your values, what choices you want your children to have and how you can best help them achieve what they want in life in a healthy and safe way.

This is the most helpful book I have read on this topic. No matter where you are in raising your child with Down syndrome, I would highly recommend you purchase this book. I promise you will take it off the shelf time and time again as you continue this journey of raising a happy, healthy and safe child.

The book is available for loan at the Down Syndrome Association of Middle Tennessee library. For information, please call 615.386.9002, or e-mail dsamt@bellsouth.net.

Sheila Moore is executive director of The Down Syndrome Association of Middle Tennessee.

CHATTANOOGA'S MAYOR'S COUNCIL on DISABILITY STRIVES *for* MORE ACCESS-FRIENDLY CITY BY JILL HINDMAN

The Mayor's Council on Disability (MCOD) was formed in late 2005 by Mayor Ron Littlefield to make the city of Chattanooga a more disability friendly city. The 15-member entity is comprised of people with disabilities, family members, service providers and employers. Council members serve for two years with the possibility of reappointment for an additional two years.

The MCOD serves as an advisory body to the Mayor and City Council on disability issues. Over the last two years, MCOD has spearheaded a number of projects for the City of Chattanooga, including an annual Americans with Disabilities (ADA) recognition event and GOFEST, a festival that celebrates people of all abilities.

Several MCOD members have spoken to different organizations in the Chattanooga/Hamilton County area, and MCOD has conducted numerous disability-related workshops for various departments within city government, including Neighborhood Services and Codes Enforcement.

MCOD is currently working with Hamilton County Emergency Management Services (EMS) to develop an emergency evacuation

CAREER DAY BRINGS HUNDREDS of HIGH SCHOOL STUDENTS to COOKEVILLE

More than 330 students, 55 exhibitors and 15 volunteers

helped make the Upper Cumberland Career Center's Career Day in Cookeville a great success! The event was organized by Danielle Cason and Charles West, who hold this annual event to inform students with disabilities about employment, leadership training and community service options following high school.

Photos by Josh Long, an employee of UCHRA



plan for Chattanoogaans with disabilities. MCOD will be assisting the EMS to identify shelters that are accessible to everyone, to develop methods for disseminating information about potential emergencies and to establish a registry for individuals with disabilities.

In addition, MCOD has consulted with city-owned and operated facilities to ensure that they are accessible to the largest number of individuals with disabilities. For example, Chattanooga's Memorial Auditorium, which will begin making renovations to the building in the next few months, took suggestions from the Council about ways to improve accessibility for patrons. Some Council members have begun the process of evaluating the city's recreational facilities for physical and programming access. To date, the facilities which have been evaluated have needed little or no renovation.

MCOD is a resource for departments within city government,

businesses and residents with disabilities or family members of persons with disabilities, especially in the areas of communication and program access. MCOD also is educating Chattanoogaans with disabilities on how to ask for and receive reasonable accommodations.

Beginning in 2008, MCOD will be working on an accessibility guide for the City of Chattanooga. The goal is to make the city a more inclusive community for all its citizens. For more information on MCOD's activities, please contact mcd@mail.chattanooga.gov.

Jill Hindman is a graduate of the first Partners in Policymaking class (93-94), a long-time advocate and currently represents the Southeast Development District on the Council on Developmental Disabilities.

Photo by Courtney Evans Taylor



For more information contact Hispanic Outreach Coordinator Claudia Avila-Lopez at claudia.avila@vanderbilt.edu or 800-640-4636 (ext. 11).



HISPANIC OUTREACH PROGRAM UPDATE

On November 7, 2007, Pathfinder's **HISPANIC OUTREACH PROGRAM** sponsored the 3rd Annual Disability Services and the Hispanic Community Conference. The conference, held at Nashville's Knowles Senior Center, facilitated resource and information sharing through a "Barriers & Possibilities" roundtable discussion. Another panel discussed information, treatment and resources related to autism and Hispanic Outreach Project collaborators shared project results and recommendations for working in the Hispanic community. Over 50 social service providers, students and community advocates attended.

Pathfinder continues to identify bilingual resources around the State. A recent Council on Developmental Disabilities grant awarded to the Memphis-based UT Boling Center will support the development of Pathfinder's bilingual resource database, Camino Seguro, in West Tennessee.

FOR FURTHER INFORMATION

Tennessee Disability Pathfinder

English & Español
(615) 322-8529
(800) 640-4636

TTY/TDD users:
please dial 711 for
free relay service

www.familypathfinder.org

tnpathfinder@vanderbilt.edu

ACCESS NASHVILLE UPDATE

ACCESS NASHVILLE, a project of Tennessee Disability Pathfinder supported by the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (UCEDD), was featured in a *Discovery* article on university student pre-service training. The article, published in the Fall 2007 edition of the Vanderbilt Kennedy Center's quarterly publication, shares how a number of professors include Access Nashville participation in their coursework. Nursing, special education and psychology students increase their awareness of the needs of people with disabilities as they identify "accessibility friendly" restaurants so that all persons can make informed decisions about where to eat.

Carole Moore-Slater, M.S., UCEDD co-director of community service and technical assistance and

Tennessee Disability Pathfinder director, helped found the program and now conducts the Nashville training sessions. Ms. Moore-Slater notes that incorporating the training into the academic setting is less expensive, more time-efficient and provides the program with more trainees. "It's a great hands-on experience for the college students," Ms. Moore-Slater said. "The response from the students has been amazing. It really makes sense because they're going to be the ones who improve the laws, change the building codes and advocate in the community." *Discovery, Fall 2007*

For more information about ACCESS

NASHVILLE, visit the project Web site at www.accessnashvilleonline.org or contact Carole Moore-Slater at 800-640-4636 ext. 13



Melissa Fortson is information & referral specialist/program coordinator with Tennessee Disability Pathfinder.



SUBMITTING AGENCY INFORMATION TO PATHFINDER JUST GOT EASIER!

Moving? Starting a new program or changing an existing one? Have a new director or contact information? Service providers can now send this information to Pathfinder's Resource Specialist via our Web site. Simply visit www.familypathfinder.org, click on "Search the Pathfinder Database for TN Services", then follow the link and instructions to provide us with your updated information. Agencies that meet Pathfinder's inclusion criteria are included in our print directory and searchable database; complete and current information also helps staff make appropriate referrals to your services. For information or assistance, contact Ashley Coulter at ashley.coulter@vanderbilt.edu or 800-640-4636 (ext. 15).

Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the **TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES** and the **VANDERBILT KENNEDY CENTER FOR RESEARCH ON HUMAN DEVELOPMENT**.

TENNESSEE MICROBOARD ASSOCIATION:

Bringing Self Determination to Community Services

BY RUTHIE-MARIE BECKWITH, PH.D. AND ALICIA A. CONE, PH.D.

In 2000, the Tennessee Council on Developmental Disabilities began exploring the concept of a microboard. We were very interested in the model started by Vela, the association in Canada that provides training and technical assistance to microboards in several Canadian provinces. As defined by Vela, a microboard is a small group of people who have formed a non-profit organization around one person with a disability. Members of the microboard include the person, his or her family and friends and other persons from the individual's community. All of the people on the microboard are committed to helping the person create and work toward a vision for his or her life.

Another way to think of a microboard is that it is a provider for one person. We researched Vela's experience in Canada as well as the current use of microboards in the United States at that time. We found only a small number of microboards operating in a handful of states in 2000.

After extensive research and meetings with several stakeholder groups, the Council determined that it was critical to have an organization that could provide support to developing microboards. This organization would have to be able to assist microboards to incorporate, navigate the provider application process, learn the procedures needed to operate as a successful provider of services and offer required or necessary training to microboard members and staff.

The mission of TMA is to promote the creation of microboards for individuals with disabilities in keeping with the principles of self-determination, freedom, authority, support and responsibility.

In 2001, the Council invited proposals for establishing a technical assistance center for Tennessee microboards. Several proposals were received and reviewed and the grant was awarded to Tony Records and Associates, which created the Tennessee Microboard Association (TMA). TMA's mission is to promote the creation of microboards for individuals with disabilities in keeping with the principles of self-determination, freedom, authority, support and responsibility.

Across the State, TMA provides support and training to individual microboards by developing materials and resources for those individual microboards. TMA begins its hands-on process by helping individual microboards in planning services and supports through PATH (Planning Alternative Tomorrows with Hope). Following the PATH

session, TMA helps in the following areas: incorporating a non-profit organization; microboard board member training and development; becoming a certified and licensed provider of services and supports; and required and advanced training for direct support professional staff hired by an individual microboard.

Currently, there are 287 individuals and family members supported statewide by TMA personnel, 83 incorporated microboards and 29 operating microboards, 24 with Division of Mental Retardation Services funding.

As TMA has grown, so has its national reputation. As the result of its listserv, individuals and family members from other states have had the opportunity to hear firsthand about the life-changing efforts of the microboards. In 2005, TMA began a concerted effort to provide technical assistance in both Georgia and Iowa. The first two microboards in those states are now awaiting approval of their provider applications. In addition to hands-on assistance, TMA has communicated with microboard efforts across the country and recently hosted a representative from Texas for three days of information sharing.

Through its national collaboration, TMA learned of another exciting method by which individuals and their families are gaining control over their services: human service cooperatives. Cooperatives are member (service recipient) owned entities that enable a number of individuals, who may not have the necessary personal networks to form a microboard, to form a provider agency. TMA brought this idea back to Tennessee and is currently working in Memphis to develop the Freedom Co-op in partnership with Gale and Holly Bohling of the Federated HSC.

All of these efforts ultimately lead to the most important outcome of all—self-determination. With the support of family and friends, individuals with developmental and other disabilities are demonstrating that they are willing to roll up their sleeves and carry out the work of being in control of their own lives.

Ruthie-Marie Beckwith is executive director of the Tennessee Microboard Association and Alicia A. Cone is project research and development coordinator for the Council on Developmental Disabilities.



TENNESSEE SPOTLIGHT

Robbie Marascia, son of Partners 06–07 grad, **Tina Marascia**, recently participated in *Reflections*, his school's annual competitive art program. Participants choose their own submission category and Mr. Marascia entered a photograph for consideration. Mr. Marascia also hit the great outdoors with the Indian Guides program, going white water rafting and camping and winning two awards for critters he found in the woods during a "hunt".

Jordan Pack, Youth Leadership Forum (YLF) 2007 grad, has been staying busy with the **Sevier County High School** bowling league, attending practices and games after school. The Sevier County league is currently tied with one other team for first place in their division. Mr. Pack's average score is 121; the team overall is undefeated, with four wins and no losses. On the creative end of the spectrum, Mr. Pack had the opportunity to design and print a program in his Graphic Art class that was handed out at the high school's Veteran's Day Celebration event this past November.

Pam Bryan, Partners 04–05 grad, has been accepted to serve as a consumer reviewer on the **Congressionally Directed Medical Research Program** (CDMRP). As a peer panelist, she will review proposals for the Fiscal Year 2007 TBI/PTSD (Traumatic Brain Injury/ Post Traumatic Stress Disorder) programs.



Photo by William Puckett Photographers

Partners 04–05 grad, **Kelly Sanders**, graduated from **Middle Tennessee State University** on August 11, 2007. She now holds a bachelor of science degree in recreational therapy.

Monica Neely, Partners 06–07 grad, was invited to become a member of the **Oakland City Parks, Recreation and Cultural Arts Board** and hopes to work hard to help make parks in her area more accessible to seniors and persons with disabilities.

Spectrum K12 School Solutions held a reception to honor **Holly Lu Conant Rees** as the recipient of their 2007 **Special Education Advocate Extraordinaire Award**. Ms. Conant Rees shared her story about how she planned to live her life away from all bureaucracy, but found herself in the midst of it as she fought for rights for her son. In her quest to see all students succeed, she has been a strong advocate on behalf of families with children with disabilities for nearly two decades. Ms. Conant Rees founded and continues to chair the **Tennessee Statewide Disability Coalition on Education** (DCE), and is an active member of the **Advocacy for the Rights of Individuals with Disabilities Organization**.

Jonathan McGee, son of Partners 00–01 grad, **Kathy McGee**, is continuing his advancement in the Boy Scouts. He has participated in many camping trips and outings and is currently serving as the Chaplain's aide. He has also earned his Disabilities Awareness Badge and received the "Scout Spirit" award at summer camp for the second time—an award voted on by his fellow scouts.

YLF 2006 graduate, **Will McMillan** (son of Partners 05–06 grad, **Elise McMillan**) has been advocating for persons with disabilities in his government class at **John Paul II High School**. As students were giving presentations on American presidents, Mr. McMillan asked about each one's stand on disability issues. Now when the students report, they always include a slide in their PowerPoint presentations on the topic of disability.

In early November, local artist, **Bernadette Resha**, and **Josh Putman** tied the knot at **Scarritt-Bennett Center Chapel** in Nashville. **The Down Syndrome Association of Middle Tennessee** invited family and friends to a reception celebrating the union on Sunday, December 9th at the **Westminster Presbyterian Church Fellowship Hall**.

Mary Claire Giffin, Partners 2007 grad, recently received the **Lori M. Siegal Partners in Progress Award** from the **Down Syndrome Association of the Mid-South** (DSAM). The award is presented annually to someone living in the Mid-South who demonstrates exemplary actions in including individuals with Down syndrome and creating awareness of the abilities of these individuals. The award was created in 2003 and re-named in 2006 in memory of **Lori M. Siegal**, the first person with Down syndrome to be elected to the DSAM board of directors and the **National Down Syndrome Congress Board**.

Ned Andrew Solomon, Partners 05–06 grad and director of the Council's Leadership Institute (Partners in Policymaking™ and The Youth Leadership Forum) was recently honored as **Planner of the Year** by the Tennessee chapter of the **Society of Government Meeting Planners**.

Betty Anderson, Partners 04–05 grad, recently began a new job as Travel Trainer for the **Memphis Area Transit Authority**. Her job is to teach people with all types of disabilities how to ride fixed route buses and trolleys and to learn about bus schedules and issues related to safely using public transportation. Her service is free of charge.

Mark Montgomery has accepted the position of executive director of the **State Independent Living Council** (SILC). Mr. Montgomery holds a Juris Doctor from the **State University of New York** with a bachelor of science in Political Science and Philosophy. Professional experience includes employment as an instructor with the **Pioneer Central School District** and research coordinator with the **Rehabilitation Research and Training Center on Independent Living Management**.



Photo by Carol Greenwald

In August, Partners 02–03 grad, **Keith Greenwald**, traveled to Kansas City to attend the **National Down Syndrome Congress** (NDSC) and to present two seminars on "A Dream Come True: Steps to Home Ownership." Mr. Greenwald co-presented with his mother, **Carol Greenwald**, and **Martine**

Hobson, a Memphis realtor with **Prudential**, board member of the NDSC and mom to YLF 2001 grad, **Laurie Hobson**.

ASA-ETC (Autism Society of America, East Tennessee Chapter) received a \$20,000 grant from the **Knights of Columbus** for start up costs for an office and for training parents of children with autism. **Beth Ritchie**, ASA-ETC Board member, was honored as part of the **Knoxville YWCA Tribute to Women, Volunteer Community Service**. After completion of the most successful ever **Autism Golf Tournament**, **John Thomas**, ASA-ETC Board member, received the *East Tennessee Golf News* award for **2007 Tournament Director of the Year**.

YLF 2006 grad, **John Matejko**, joined marathon runner, **Tim Borland**, when he made a stop in Nashville during his incredible run of 63 marathons in 63 days. Mr. Borland was trying to increase awareness and find a cure for **Ataxia-Telangiectasia**, or simply A-T, a rare genetic disease that affects children and combines symptoms of cerebral palsy, muscular dystrophy, cystic fibrosis, cancer and immune deficiencies. Videos of Mr. Matejko's participation have surfaced on **You Tube** and other Web sites and his picture graced the cover of the December 2007 issue of *FFA (Future Farmers of America) New Horizons*.

The winners of the **2007 Mayor's Advisory Committee for People with Disabilities** (the 26th annual) were recently announced at a ceremony at the **Adventure Science Museum** in Nashville. The event was co-sponsored by the **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities** (VKC) and, along with the awards

listed below, featured beautiful artwork included in the VKC's **Creative Expressions XIII** art exhibit. The artists with disabilities represented were **Anne Ambrose, Grace Goad** (daughter of Partners grad, **Leisa Hammett**), **Laura Hudson, Penny Hunter, Claudyne Jefferson, Karri Kelley, Mari Amanda Lund, Susannah Mayhan, Delsenia Sales, Kathy Tupper, Foster Williams, Anita Wilson** and **Nora Jean Wood**.

The Awards:

Mack West Children's Award: Kira McCall

Trey Pointer Young Citizen Award: Palmer Harston and Amy Saffell

Jo Andrews Award: Mark Singer

Professional Award: Pam Bryan (Partners 04-05 grad) and Sara Ezell (Partners 04-05 grad and current At-Large Council member)

Volunteer Award: Anais Wolfe-Mazeres

Family Award: The Heil Family

Health Care Provider Award: Katherine Hall, DDS and Laura Lekowicz

Media Award: Nashville Talking Library

Artist/Entertainer Award: Massood Taj and Yvette Parrish

Employer Award: Goodwill Industries of Middle Tennessee

Agency/Organization Award: Prentice and Becky Huffines and Members of Old Hickory Country Club

Educator Award: Malinda Murphy



TENNESSEE DISABILITY PATHFINDER 2007-2008 DIRECTORY ORDER FORM

The **2007-2008 Disability Services & Supports Directory** is published by Tennessee Disability Pathfinder. It is a source of information regarding state and local programs and services. The manual provides detailed information about each agency, including contact information, address, email, Web site, keyword service categories with program descriptions, counties served, non-English speaking staff availability and office accessibility. It is offered in East, Middle and West regional editions for \$25 each.

If you have any questions, email Ashley Coulter at ashley.coulter@vanderbilt.edu.



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